Supporting People with Dementia Using Pervasive Healthcare Technologies

Chapter 1
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Abstract In this chapter, an introduction is provided into pervasive healthcare technology, specifically as the use of information and communications technology in support of European policies, primarily inclusion. The focus of the chapter, and indeed the book, is on how such technologies can support people suffering from debilitating diseases including Alzheimer's. The work describes a research project called COGKNOW, comprising a multidisciplinary research consortium of scientists from across Europe, and relates some of the early achievements of the group from some very different perspectives, including technical, clinical, ethical, and of course how the needs of people with dementia and their carers can be harnessed in the development process to produce pervasive healthcare technology and services that are valued by all the stakeholders in the process.

1.1 Introduction

In Europe by 2050, it is estimated that one-third of Europe's population will be over 60. The number of "oldest old" aged 80+ is expected to grow by 180% (Eurostat 2002). For example, in 1951, there were 300 people aged 100 and over in the UK. By the year 2031, it is estimated that this figure could boom to 36,000 (BBC 2007). Life expectancy has been rising on average by 2.5 years per decade in Europe. There are 5.5 million cases of Alzheimer's disease in Europe and more new cases per year.

Technology has the potential to improve and extend the quality of life of older people and people with disabilities by helping them to lead fuller and more independent lives. It can also improve the efficiency and effectiveness of services provided to older people and people with disabilities and so help to constrain the cost and

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improve the quality of care. Such technology can also extend their economically active life. Technology has significant potential for curbing the ever-increasing costs of caring for the elderly and the disabled.

The technical concept in COGKNOW is to develop a portable, remotely configurable mobile device and service which does not require complicated instructions or manipulations on the part of the elderly citizen, but which can aid the citizen to navigate through their day, unobtrusively offering information and reassurance, while allowing the citizen to structure their timetable and to retain greater control over their daily life activities. The consequences for greater autonomy and the empowerment to control one's own life into old age are considerable.

The core scientific and technological objective of COGKNOW is to achieve a breakthrough in the development of a successful, user-validated cognitive prosthetic device with associated services for people with mild dementia. This entails cognitive reinforcement in the four main areas of helping people to remember, helping to maintain social contact, helping with performing daily life and recreational activities, and providing enhanced feelings of safety (Meiland et al. 2007). In the COGKNOW project, we have sought to address this core objective by focusing on scientific and technological objectives for the device, including remotely configurable reminding functionality, communication and interaction functionality, supportive technology for performing Activities of Daily Living (ADLs), and anomaly detection and emergency contact.

1.2 Why Select Mild Dementia?

The choice of application area (elderly people with mild dementia) was chosen in response to the knowledge of the growing presence of this condition in an increasingly ageing population; of the Europe-wide presence of this condition and of the "demographic time-bomb" which threatens in the near future if measures are not taken to support elderly people with mild dementia to increase their autonomy and self-help; of the common need being perceived across Europe to find remedies to ameliorate the effects of dementia; and of the potential in reduction of healthcare costs by allowing the citizen to remain in their own home environment unassisted by carers for longer than would currently be the case.

Dementia is a progressive, disabling, chronic disease affecting 5% of all persons above 65 and over 40% of people over 90 years (Fratiglioni et al. 2000; Launer and Hofman 2000). The term dementia refers to a combination of symptoms involving impairments of memory, speech, thought, perception, and reasoning. Early impairments in performing complex tasks lead to an inability to perform even the most basic functional activities such as washing and eating. Often there are changes in personality, behaviour, and psychological functioning, such as depressive symptoms, apathy, and aggression. These neuropsychiatric symptoms appear to afflict the overwhelming majority of sufferers and are reported to be particularly potent precipitants of institutionalisation (Craig et al. 2005; Mirakhur et al. 2004).

The most prevalent type of dementia in the elderly is Alzheimer's disease (AD). Two-thirds of older people and one-third of younger patients (50–65 years old) with dementia have Alzheimer's disease. We propose to develop COGKNOW in a cohort of AD patients with mild impairments in cognition and function. Alzheimer's disease sufferers represent by far the most common cause of dementia throughout Europe and display a clinical course that is typically only slowly progressive. This allows the user to enjoy the eventual benefits of COGKNOW over a longer time frame (until that point is reached when severe disability intervenes) and also permits better standardisation during COGKNOW field trials where a rapidly fluctuating clinical course might impede the assessment of user need and system efficacy.

There exist relatively few studies in which persons with dementia were surveyed and allowed to describe their own specific unmet needs. Aside from physical problems (such as loss of eyesight and hearing and incontinence) the most frequently identified unmet needs are in the areas of information (on condition, treatment, care and support possibilities, appointments with care services, etc.), memory problems, and communication and psychological distress (anxiety) (Walters et al. 2000; Beattie et al. 2002, 2004; van der Roest et al. 2005). A report examining quality of life issues of dementia sufferers has recently identified seven key domains (Dröes et al. 2005): physical and mental health, social contact with family and friends, being useful to others, enjoyment of activities, self-esteem (being respected by others), and self-determination and freedom.

A different personal perspective and lack of insight into their predicament cause patients to report less needs, and in some cases different needs, than their carers (Hancock et al. 2003; van der Roest et al. 2005). In one study the needs identified by the informal carers were associated with their own mental health (Hancock et al. 2003), suggesting that the greater need of the carers could also be related with the mental health problems of the carers themselves. Unmet needs mentioned by both patients and carers include

- Memory problems of the person with dementia,
- Communication,
- (Enough) meaningful activities during day time,
- (Feelings of) safety, and
- Information (on the disease, prognosis, care policy, possible care and support services, appointments).

If we analyse these needs as described above from various studies, we can see the importance of various strands of the person's life, including feeling of autonomy, that needs reinforcement of orientation in space and in time, of topographic memory and of (auto-) biographical memory, and the ability for the person to maintain contact with their social environment and improve their relationship with it and their peers. This involves not only reinforcement of identity, episodic memory, and assisting the fight against apathy, but also facilitation of all aspects of communication and motivating people to express their opinions and thoughts and wishes and fears and

reinforce their feelings of social belongingness and of references that ground people temporally.

1.3 The European Policy Landscape

In Europe, policy that supports people with disabilities, ageing people, and other groupings of people that can potentially suffer from physical, digital, or social exclusion is termed "inclusion" policy. The following sections of this chapter outline the strands of this policy as they impact on "inclusion" research.

1.3.1 Demographic Ageing

Europe is an ageing continent. Of the 458 million people in Europe almost one-sixth are aged over 65, which is 76 million (European Commission 2005). It is estimated that this proportion will have risen in some Western European countries up to one in four people in 2025 (US Census 2000), with the largest increase in the oldest (80+) age group, where disability is most prevalent (Lamura 2003): The number of people aged over 80 will rise from 18.8 million today to 34.7 million in 2030, due to the ageing baby-boomer generation and a significant increase in life expectancy resulting from improved conditions of life and improved medical practice (European Commission 2005). With the increasing number of elderly the number of disabled people will also increase, which amounts to a demographic "time bomb".

These demographic changes mean that the countries of Europe can expect a massive rise in the number of older people and a corresponding increase in the number of dementia sufferers. If one considers the associated costs of community-based caring strategies and the emotional and economic burdens associated with institutionalisation, it is clear that these unfortunate individuals must be considered in the context of both national and European healthcare strategies, as well as social and economic policies.

Based on the prevalence rates of EURODEM (Hofman et al. 1991) and population statistics from Eurostat, Alzheimer Europe has estimated the number of people with dementia in the age of 30 and older in Europe as 5,709,348 (Alzheimer Europe 2005). Among the elderly population in Europe about 5% suffer from dementia (3.8 million people). This percentage is based solely on diagnosed cases. This is likely to lead to an underestimation, because many people with dementia never receive a diagnosis and it excludes those in the early stages of dementia who have not been diagnosed (Alzheimer Europe 2005). In COGKNOW, the focus has been on the real needs and wants of people with mild dementia, that is, at least half of those suffering from dementia in the elderly population. Approximately 1.9 million elderly people in Europe experience mild dementia. This is the potentially excluded section of Europe's population that the project is seeking to assist. This figure is expected to double in the coming four decades (Health Council 2002; European Commission

2005). Thus, the COGKNOW project and equivalent research have the potential for a fundamental and sustainable impact on the development of future applications and services to support ageing people with dementia and improve their quality of life.

1.3.2 The Care Burden

Due to the growing number of ageing people, there are, and will be, long waiting lists for sheltered housing projects, homes for the elderly, nursing homes, and other care facilities. The majority of people with dementia will have to "survive" in their own homes. Furthermore, most elderly people wish to stay at home as long as possible. This on the one hand releases the pressure on the nursing homes, yet generates great pressure on informal carer(s), such as spouses, children, other family members and friends, also because of the increasing shortage of professional carers. Taking care of a person with dementia is recognised as a burdensome task (European Commission 2005). Many informal carers experience negative physical, psychological, and social consequences that besides the behavioural problems of the person with dementia are important determinants of nursing home admission of the person with dementia (Teri 1997; Braekhus et al. 1998; Aalten 2004).

Research projects such as COGKNOW can potentially help to address these societal problems by investigating how technology can be used to improve the autonomy and the quality of life of elderly people, so that people with dementia can stay longer in their own homes with a better quality of life. It is to be expected that supportive measures that increase the autonomy and quality of life of the persons with dementia will not only help the patient but will also relieve the burden for the carer.

1.3.3 European Policy Areas

European policy makers face significant challenges as they strive to retain clarity and cohesiveness across the broad policy domains of *inclusion* policy and the *information* society policy.

These two policies are interweaved in parts of the major initiative "i2010: European Information Society 2010", promoting an inclusive European information society. To close the gap between the information society "haves and have-nots", in 2007 the Commission proposed a "quality of life" Information and Communication Technology (ICT) flagship initiative on technologies for an ageing society. In 2008, the Commission also proposed actions to overcome the geographic and social "digital divide", culminating in a European Initiative on e-Inclusion.

The call for proposals to which COGKNOW and other related ICT for Inclusion projects responded articulated the challenge "to develop next-generation assistive systems that empower persons with (in particular cognitive) disabilities and ageing citizens to play a full role in society, to increase their autonomy and to realize their potential".

In Europe, therefore, the European Commission is identifying areas where research can help to devise new breakthroughs using ICT to address policy challenges strategically.

1.4 Pervasive Healthcare Technology and Services

Previous research in cognitive prosthetics has delivered devices and services which have had mixed or little success when applied to actual living conditions among ageing people with dementia (Lauriks et al. 2007). However, they have proven useful in highlighting where gaps in service and autonomy may be filled. The COGKNOW project outlined in subsequent chapters is focused on addressing these gaps and on delivering pervasive healthcare services and technology that makes a difference in actual living conditions.

The analysis of the state of the art of ICT solutions by the COGKNOW consortium for dementia sufferers showed that various types of services and several products are available for all the most frequently mentioned unmet needs. In the current market there are relatively simple products such as automatic pill dispensers or telephones with the photos of the persons frequently called, which contribute to the support for memory and social contacts, to more complex and complete tracking devices, using Global Positioning Systems (GPS), that also assist in locating people with dementia when they happen to "wander". The beneficial effects of computer systems have been observed on orientation, feelings of anxiety, and independency in patients suffering from Alzheimer's disease. Besides this, implementing monitoring technologies and detection devices or alarm systems inside and outside the home of elderly persons is potentially useful to enhance (perceived) safety and security of the person suffering from dementia as well as carers.

New technologies have also a remarkable role in assistive cares. Internet-based applications designed to provide carers with clinical, decision-making, and emotional support have been evaluated in field trials and the initial results have shown the system to be beneficial both to carers and to people with dementia (Lauriks et al. 2007). Nonetheless, despite all these pervasive healthcare services, products and technologies available to enhance and improve Alzheimer patients' quality of life, there is no system in the current market capable of offering help and solutions that cover the four main need areas previously mentioned.

This was the core rationale for the project. COGKNOW offers the potential to be a valuable approach, which implements a wide range of services that not only will help people with dementia to face up to their main needs, but also makes it possible that they can lead a normal life, included in society. The European Commission stated, "We have to apply technology to the task of genuinely empowering citizens to play a full role in society." This was our goal in COGKNOW.

The following sections outline the main areas covered by the book, namely, Sections 1.5, 1.6, 1.7, and 1.8. In each of these sections, the constituent chapters are summarised and placed in context.

1.5 Background to the Research

In this section, there are four chapters, covering medical aspects of dementia, the state of the art in electronic assistive technologies for people with dementia, a detailed chapter reviewing ICT-based services for identified unmet needs in people with dementia, and a chapter describing the issues relating to privacy, ethics, and security when designing solutions for people with dementia.

In Chapter 2, a short introduction to key aspects of this disease and its various forms is provided. The chapter begins be defining the disease and providing a historical background before describing the extent of the disease. The health economic impact of dementia is presented, together with an outline of the sub-types of dementia before the relationship between the disease and age is discussed. The risk factors associated with dementia are enumerated, and the important issue of the impact of the burden of the illness for carers and person with dementia is discussed before management aspects for the disease are presented.

In Chapter 3, the case is made of the effectiveness of pervasive healthcare technology and services in catering for the main needs of people with dementia. However, despite advances in information and communication technologies and growing sales, industry has been slow to standardise these technologies and to implement them. Because of this, in last years in Europe, there have been a large number of initiatives, both public and private, which seek to improve the situation of those persons who suffer from dementia. These initiatives and technologies are the focus of this chapter.

In Chapter 4, the authors present a systematic review of the needs of people with dementia and their carers that may be addressed by pervasive healthcare technologies and services. This chapter, then, provides an insight into the state of the art in ICT solutions that could contribute to meet the most frequently mentioned unmet needs by people with dementia and their informal carers. These needs can be summarised as the need for general and personalised information; the need for support with regard to symptoms of dementia; the need for social contact and company; and the need for health monitoring and perceived safety. The findings outlined in this chapter conclude that informational websites offer helpful information for carers but seem less attuned to the person with dementia and do not offer personalised information. The chapter also describes how ICT solutions aimed at compensating for disabilities, such as memory problems and daily activities, demonstrate that people with mild to moderate dementia are capable of handling simple electronic equipment and can benefit from it in terms of more confidence and enhanced positive affect. Finally, the chapter describes how instrumental ICT support for coping with behavioural and psychological changes in dementia is relatively disregarded as yet, while support for social contact can be effectively realised through, for example, simplified (mobile) phones or videophones or (entertainment) robots. The chapter concludes by recommending that future studies also focus on the integration of the current techniques and solutions.

In Chapter 5, pervasive healthcare technology options relating to the users are discussed before examination of the ethics, privacy, and security issues are described

in detail in the context of provision of technology to assist people with dementia. New and emerging technologies provide the opportunity to develop innovative sustainable service models, capable of supporting adults with dementia at home. The findings of the chapter relate that ethical issues abound in all aspects of interventions to support adults with dementia. The chapter relates that the service context for pervasive healthcare technologies is often complex, involving a variety of stakeholders and a range of interested agencies. Against this backdrop, it is critical that due consideration is given to the potential ethical ramifications at an individual, organisational, and societal level.

1.6 The Role of the User in the Design Process

In this section, there are three chapters, examining first the identification of the needs of users in the participative design process that drives the research, how to manage the transition from the resultant user information on needs to functional requirements and subsequent technical specifications used by the system designers and finally recounting the lessons learned from field trials about which dementia-related and other factors need to be taken into account in the development process.

In Chapter 6, the process of identification of the needs of people with dementia (and their carers) is described. The design process consisted of iterative cycles at three test sites across Europe, with active participation by people with dementia and their carers in the developmental process. Based on their priorities of needs and solutions, on their disabilities and after discussion between the development team, a top four list of ICT solutions was made which served as the basis for development. These areas are in the area of remembering – day and time indication and reminding service, in the area of communication – picture dialling function, in the area of daily activities – media playback and radio function, and finally, a warning device for an open front door and an emergency help contact to enhance feelings of safety.

In Chapter 7, the management of the process that bridges the large gap between user studies and the design of the system is described. This process consists of two smaller steps: the transition from user requirements to functional requirements and from the latter to the technical specification.

Chapter 8 focuses on how issues which affect people with dementia, such as failure of prospective memory, can be taken into account as the pervasive healthcare technologies and services from COGKNOW are developed. The main dementia-related disabilities that emerged from the users and that proved relevant for the development of an assistive technological device were memory and orientation problems; poor understanding of verbal instruction; difficulty with instrumental daily activities; and recognising/understanding the meaning of pictures. Relevant personal and environmental features were living alone or with a carer; the need for company and social contact; the need for support in doing things for fun; using aids like a walking cane; possessing technological appliances that could not be easily used anymore; living in a house with multiple rooms and levels; and feeling insecure

when being alone. After a development period, the user-friendliness and usefulness of the device developed to assist people with dementia were assessed via field trials. Using semi-structured interviews and observations, the experiences of the people with dementia and carers with the devices were inventoried. It was concluded that though most functions were judged as user-friendly and useful, further personalisation of the device interfaces would improve the perceived user-friendliness and usefulness. This study showed that detailed information on the functioning and living environment of the users is necessary to attune technology to their needs. The group of people with dementia that participated in this work also showed that people with mild dementia are very capable of giving their opinion on the user-friendliness and usefulness of assistive technology.

1.7 Pervasive Healthcare Technology

In this section, there are three chapters describing different aspects of the technology used in the development of a solution in the project. The role of context-aware computing in support of people with dementia is described in Chapter 9, before Chapter 10 outlines the process of prototyping and development of the technical devices and services. The final chapter in this section examines research in interface design for ageing people in general and in particular for people with dementia.

In Chapter 9, an introductory tutorial on context aware computing is provided, describing the origins of the technology and its importance with respect to location-based computing, encompassing large-scale environments as well as those of a smaller scale, such as “smart homes”. The potential for computing to be able to use context-awareness information to predict such things as anticipated activities of daily living and then to offer supporting interventions is described before the applicability of such technology for people with dementia is described.

In Chapter 10, the development of a cognitive prosthetic to address the unmet needs and demands of persons with dementia through the application of ICT-based services is described. The primary aim of the developed solution was to offer guidance with conducting everyday activities for persons with dementia. The chapter describes how, to encourage a user-centred design process, a three-phased development methodology was introduced to facilitate cyclical prototype development. At each phase, user input was used to guide the future development. As a prerequisite to the first phase of development, user requirements were gathered to identify a small set of functional requirements from which a number of services were identified. Following implementation of these initial services, the prototype was evaluated on a cohort of users and, through observing their experiences and recording their feedback, the design was refined and the prototype redeveloped to include a number of additional services in the second phase.

In Chapter 11, an overview of the research and literature relating to ageing people and people with dementia is provided. The chapter also discusses the differing contexts in which ageing people interact with computerised systems and their associated issues.

1.8 Evaluation and Assessment of Cognitive Prosthetics

In this section, there are three chapters, beginning with a short chapter looking at the important practical issues involved when planning for the field trials with users. The second chapter provides a detailed examination of the process of evaluation of the cognitive prosthetics developed in the research, while the final chapter in this section describes how the COGKNOW team planned and executed the process to measure the impact of cognitive prosthetics on the daily life of people with dementia and their carers.

In Chapter 12, the role of planning and timing of field trials when testing technical solutions is described. This short chapter is written from a test site leader perspective and describes the experiences of setting up the first and second field trials in the three test sites of the COGKNOW project. The chapter addresses issues in the preparatory, the actual and the post-test phase of the field trial in order to help achieve a high level of success both from a general perspective and with a special focus on people with dementia.

In Chapter 13, the evaluation of the usefulness and user-friendliness of the first COGKNOW device is described. The chapter also draws together experiences drawn from the evaluation process, together with reflections and guidance for those contemplating field studies using pervasive healthcare technologies. The experiences from the testing process have so far shown that the use of a mix method approach using semi-structured interviews, combining structured and open questions, and semi structured observation provides a comprehensive understanding of the usefulness and user-friendliness that overcomes some of the challenges.

In Chapter 14, the COGKNOW project is used as a case study example in order to explain how the impact of cognitive prosthetics on the daily lives of people with dementia and their carers can be measured. Devices have been developed with an aim to improve the quality of life and autonomy of people with dementia and to help them to remember and remind, to have social contact, to perform daily activities, and to enhance feelings of safety. For all these areas, this chapter describes the potential instruments that can be used to measure, for example, semi-structured interviews and observations, diaries and in situ measurement.

1.9 The Way Ahead

For the final chapter, the COGKNOW researchers invited a world-respected researcher, external to the consortium, to assimilate the preceding chapters in the book, and provide a glimpse into the future of pervasive healthcare technologies and services for people with dementia.

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